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ABSTRACT

In an investigation of the impact of the psychological/educational diagnostic process on the parents of young children at risk for developmental delay, 18 families completed questionnaires and were interviewed concerning their child's evaluation. Transcribed interviews conducted 1-2 weeks after the evaluation and 4 months after the evaluations were analyzed to determine validity of predicted ratings. Data analysis addressed four areas: (1) identification of themes (including outside factors affecting parental reactions, parental relationships with the evaluator, parental involvement in the evaluation, and parents' perceptions of the validity of the child's performance); (2) comparisons across time; (3) parents' ratings of evaluation features, and (4) relationships between evaluation features and parent reactions (including the finding that parents with more involvement during the evaluation appeared to remember more information from the evaluation). Results were used to devise a model for developmental evaluations that seeks to meet parents' needs at the time of their child's evaluation. The model is designed to establish a comfortable relationship between the parent and the evaluator, convey clear and specific information to parents, and use information from parental observations in the evaluation findings. (CL)

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FINAL REPORT

IMPACT OF THE DIAGNOSTIC PROCESS ON PARENTS OF INFANTS AND PRESCHOOL CHILDREN

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Student Initiated Research Program
U. S. Department of Education
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TABLE OF CONTENTS

I. PERFORMANCE REPORT 1

A. Project Description 1

Study Participants
Procedure for the Inquiry

B. Analysis and Results 2

Interview Themes
Pre-evaluation Questionnaire Themes
Comparisons Over Time
Analysis of Parents' Ratings of Evaluation Features
Possible Relationships Between Evaluation Features and Parents Reactions

C. Implications of the Study Results 8

D. Dissemination 9

E. Project Timeline 10

II. FINANCIAL REPORT 11

III. TABLES 13

PERFORMANCE REPORT

Proposal Title: Impact of the Diagnostic Process on Parents of Infants and Preschool Children
Project Director: Terrence N. Tice
Student Researcher: Janice L. Hanson
Institution: University of Michigan; School of Education; East and South University Avenues; Ann Arbor, Michigan 48109
Grant Number: G008100039
Project Number: 023AH10006
CFDA: 84.023A

Project Description

The purpose of the study supported by this grant was to investigate the impact of the psychological/educational diagnostic process on the parents of young children at risk for developmental delay. The two major objectives of the project were (a) to describe the diagnostic process from parents' perspectives and (b) to discover possible relationships between specific aspects of the diagnostic session and certain parental reactions to the evaluation. Throughout the study, the interest was the parents' experience of the diagnostic process. The open-ended, exploratory, but in-depth research provided hypotheses and focal points that grew out of the observations and interviews as the study proceeded.

Study Participants

Twenty-five families participated in the study process of observations and interviews. Of these, eighteen families completed the process and met all of the following criteria:

1. They had a child at risk of developmental delay.

2. The children's ages fell between 3 and 34 months at the time of the evaluation.

3. The developmental evaluation observed for the study was the first of its kind experienced by the parents.

4. The children lived with at least one natural parent.

5. The parents spoke English.

The eighteen evaluations observed for the study took place at four different agencies: a genetics department in a hospital; an agency that provided physical therapy, occupational therapy, and speech therapy for individuals with special needs; a follow-up clinic for babies who had been in a neonatal intensive care unit; and an agency that located programs and coordinated services for individuals with special needs. Summarized information about the study participants appears in Table 1.

Procedure for the Inquiry

The researcher moved through the following process with each family in the study:

1. Before the child's evaluation, each available parent completed a questionnaire.

2. The researcher observed each child's evaluation with the parents, compiling a detailed written description of the session and completing a series of ratings after each evaluation.

3. The researcher then made a series of guesses about the parents' responses to the evaluation by completing another series of ratings and recording several reasons for each predicted rating.

4. The parents participated in a tape recorded, open-ended interview one to two weeks after the child's evaluation. They also completed a Likert-type questionnaire about characteristics of the evaluation. After the interview, the researcher typed a transcription of the interview, completed a series of ratings to compare with the predicted ratings, and used a new set of ratings to predict the parents' long-term responses to the evaluation.

5. The parents participated in a second tape recorded, open-ended interview four months after the child's evaluation. After this interview, the researcher again typed a transcription of the interview and completed a series of ratings to compare with the predicted ratings.

The original project proposal contains copies of the forms, questions, and rating scales used during this research process.

Analysis and Results

The analysis of data from the study covered four areas: (a) identification of themes, (b) comparisons across time, (c) analysis of parents' ratings of evaluation features, and (d)

explorations for relationships between evaluation features and parent reactions. Each of the four areas included two analysis procedures. Table 2 lists each procedure along with the questions it addressed, the product that resulted from this procedure, the function of the results of the procedure, and the relationship between these results and the implications of the study.

Interview Themes

Analysis of the interview transcriptions yielded the following themes:

Recurring Themes--Presented Topically
Based on Interviews with Eighteen Families

I. Outside Factors that Parents Bring to Evaluations and that Can Affect Their Reactions

Frequency

18 Parents observe their children carefully at home, noting what they do and do not do. Parents generally know how their children are doing.

17 Parents tend to measure their children's development by comparing it to that of other children--their other children or those of neighbors, relatives, friends--or they note that no others are available to them for comparison.

14 Parents need to feel hopeful or reassured about their children.

12 Parents feel willing to do anything to help their child; they want to do something and need to feel that they have done everything possible.

8 Parents of children with special needs seek other parents of children with similar needs to share with.

7 Parents find it hard to deal with uncertainties about their children's futures.

6 Parents tend to blame themselves for developmental deficiencies in their children.

3 Parents tend to relate the child's size to expectations of abilities, sometimes more than age.

3 Delay becomes more evident to parents from their own observations as their child grows older.

3 Having a child that parents feel has no major problems makes the evaluation a low stress situation.

II. Parents' Relationship with the Evaluator

Freguency

15 Evaluator warmth helps establish a comfortable atmosphere for questions, comments, and meeting needs.

13 The evaluation works best in the context of an ongoing relationship with the evaluator, with some contacts and after the evaluation.

12 Parents appreciate it when evaluators seem willing to spend time with or for them, and are frustrated when evaluators are not willing to do this.

11 Parents especially appreciate when the evaluator is sensitive to their child--treats their child "right."

9 Parents look for an evaluator who is an expert, who knows, who is professional and competent--and they want this to help their child.

4 Parents find it easier to relate to only one or two professionals at one time.

4 Parents are impressed by prompt follow-through by the agency, and are bothered by lack of follow-through.

3 Parents want professionals to recognize that they know the most about the child, and to listen to them.

III. Information Desired by Parents

Frequency	
18	Parents want information from the evaluator.
10	On the day of the testing, parents like some information about how the child did, although they often realize that the evaluator may need time to study the details of the test.
6	Though wanting information, parents often do not know what questions to ask.
6	Not knowing what to expect from the evaluation increases anxiety. The first evaluation is especially hard, because parents do not know what to expect from the process or the results.
3	Demonstrations of recommendations are retained well.

IV. Parents' Involvement in the Evaluation

Frequency	
18	Parents are not sure what the evaluator expects their role to be in the evaluation.
11	Two-parent families generally want the father involved in evaluations, especially to hear results.
10	Being present during testing helps parents.
9	Parents do not mind answering a lot of questions if they consider them relevant. Questions may even be helpful, because they give the parent a chance to add things that the evaluator misses while watching the child.

V. Parents' Perceptions of the Validity of the Child's Performance

Frequency	
17	Parents want their children to do for the evaluator what they do at home. If they do, it helps parents to see the test as valid. If they do not, they feel bothered and see the test as invalid.

12 Parents often have concerns about the validity of their child's test performance.

Pre-evaluation Questionnaire Themes

Analysis of the comments that parents wrote on the pre-evaluation questionnaires yielded the following themes:

Questionnaire Themes--Presented Topically

I. Outside Factors that Parents Bring to Evaluations and that Can Affect Their Reactions

Frequency

22 Most parents come to evaluations with an accurate sense about whether there is or is not cause for concern about their child's development or a need for special help.

21 Most parents have a hard time placing age levels on their children's development in specific areas.

19 Parents come to evaluations with willing attitudes about participation in programs for their children.

II. Parents' Relationship with the Evaluator

Frequency

19 Parents come to evaluations aware of the importance for their children's development of their care and play with the children at home.

III. Information Desired by Parents

Frequency

22 Parents hope to leave the evaluation with some concrete, new information.

17 Few parents have clear expectations about what will happen at an evaluation;
19 usually no one explains this before they go to the evaluation.

Comparisons Over Time

After tabulating the frequency of occurrence of the themes from the pre-evaluation questionnaire and the two sets of interviews (i.e., initial interviews and follow-up interviews), the researcher compared the content of parents' concerns before their child's evaluation with their concerns soon after the evaluation and their concerns four months later. These comparisons showed very little difference in the occurrence of themes at the different times during the study. The stability of parents' concerns over time seemed to underscore the importance of the themes that emerged from the study. The one area that did show some difference between the initial and follow-up interviews regarded the parents' own involvement in the evaluation. Thoughts about their own involvement seemed to be somewhat less on the parents' minds four months after the evaluation. The other point that became clear from these comparisons was that, although parents entered the evaluations with desires for a great deal of information, their expectations and knowledge about the evaluation process were not formed well enough to enable them to ask all the questions needed to obtain the information they desired. This implies that evaluators have a responsibility to offer a wide variety of information without depending on parents' questions, as well as to help parents formulate questions as an evaluation proceeds.

Analysis of Parents' Ratings of Evaluation Features

Analysis of the Likert-type scale that parents completed during the initial interviews involved some of Tukey's recommendations for exploratory data analysis (Tukey, John W. Exploratory Data Analysis. Philadelphia: Addison-Wesley, 1977.). The resulting charts suggested that the parents in the study (a) generally felt satisfied with the evaluations as they experienced them and (b) supported the concepts in the interview themes by rating the related questionnaire items as important to them. Parents' responses to the questionnaire items did qualify some of the interview themes by suggesting that (a) the parents preferred referral to other parents of children with the same difficulty as their own, rather than to parents of handicapped children in general; (b) the parents did not desire to receive books or pamphlets at the developmental evaluation; (c) having the evaluation conducted in a familiar place was not important unless it affected the child's test performance; and (d) while having a spouse present to participate and learn from the evaluation was important, it was not important to have another person present as a source of emotional support.

Possible Relationships Between Evaluation Features and Parent Reactions

Detailed comparison of the initial interview ratings and the follow-up interview ratings, using a procedure developed for this study, suggested the following possible relationships between the evaluation characteristics and outcomes:

(a) Parents with more involvement during the evaluation seem to remember more information from the evaluation.

(b) Parents who have an opportunity to contribute information about their child and to gain a good understanding of the purposes and meaning of developmental tests tend to see an evaluation as more fair in representing their child's abilities.

(c) Parents' level of satisfaction with an evaluation appears to be affected by many different characteristics of the evaluation; no one feature holds overriding importance.

Finally, the researcher identified the correct predictions of parent responses to the evaluations and identified themes in the reasons underlying these accurate predictions. This led to a collection of specific statements about parents' reactions to various features of the evaluations they experienced. These statements hold numerous implications for the design of developmental evaluations.

Implications of the Study Results

The researcher used all of the analysis results to devise a model for developmental evaluations that seeks to meet parents' needs at the time of their child's evaluation. The model incorporates three aims: (a) to establish a comfortable relationship between the evaluator and the parents and child, setting the evaluation in the context of a continuing relationship with contacts between evaluator and family before, during, and after an evaluation; (b) to convey clear and specific information to parents regarding the purposes of developmental evaluation, what will happen during an evaluation, what their roles as parents include during an evaluation, the meaning of the test, the implications of the child's performance, and approaches to the child's developmental needs; and (c) to gather and incorporate information from parent regarding their observations of their child at home, a comparison between the child's test performance and the child's behavior at home their needs and concerns about their child, and ways to arrange the test

situation to encourage the child's best performance. The model provides a series of checklists that detail points that an evaluator can incorporate to meet parents' needs. These checklists cover the following areas: (a) talking with parents before a developmental evaluation, (b) enhancing the relationship between evaluator and family, (c) information parents desire from developmental evaluators, (d) suggestions for parent involvement during developmental evaluations, and (e) suggestions for follow-up interactions with parents.

In the full dissertation report of the study, other implications are described for professionals who refer children for developmental evaluations, for parents and those who lead parent seminars, and for researchers who desire to pursue this topic further.

Dissemination

The following dissemination activities have occurred from this project:

(a) Hanson, Janice L. Impact of the Diagnostic Process on Parents of Infants and Preschool Children. Paper presented at the Annual Conference of the California State Federation, Council for Exceptional Children. San Diego, California. November 1981. Copies of paper distributed to session participants.

(b) Hanson, Janice L. Impact of the Diagnostic Process on Parents. Paper presented at the 61st Annual International Convention of the Council for Exceptional Children. Detroit, Michigan. April 1983. Abstracted in Exceptional Child Education Resources and Resources in Education, The ERIC Clearinghouse on Handicapped and Gifted Children, December 1983. Copies of paper distributed to session participants and to the agencies that participated in the study.

(c) Hanson, Janice L. Effects of Developmental Evaluations on Parents of Infants and Young Children. Dissertation submitted in partial fulfillment of the Ph.D. degree in Education, University of Michigan, March 1984. Abstracted in Dissertation Abstracts International. Copies of dissertation distributed to interested colleagues.

In addition, the researcher has submitted a proposal to present the model for developmental assessments that emerged from the study to the 63rd Annual International Convention of the Council for Exceptional Children in Anaheim in April 1985, and another proposal to present a position paper on parent involvement in developmental assessments to the North Carolina Association for Infants and Families in Charlotte in October 1984. She also plans

to write at least one journal article and possibly a manual for developmental evaluators, and to submit them for publication at a later date.

Project Timeline

The researcher encountered several unanticipated problems that altered the timeline projected in the original project proposal. First, referrals for subjects from the agencies that participated in the study came very slowly and followed a different pattern than that expected. Consequently, data collection proceeded through December 1981 and involved 25 families (including several incomplete cases and several families who participated but who did not meet all of the criteria for inclusion in the formal analysis discussed above) rather than the planned 15 families. The longer period for data collection and larger volume of data than expected, coupled with the fact that interview transcription took a great deal more time than expected, led to a much longer time period for the study than originally projected. All of the activities outlined in the project proposal have occurred, as outlined above, but over a longer time period than anticipated.

FINANCIAL REPORT

Proposal Title: Impact of the Diagnostic Process on Parents of Infants and Preschool Children
Project Director: Terrence N. Tice
Student Researcher: Janice L. Hanson
Institution: University of Michigan; School of Education; East and South University Avenues; Ann Arbor, Michigan 48109
Grant Number: G008100039
Project Number: 023AH10006
CFDA: 84.023A

	Allotted in Budget	Used	Remaining
1. Supplies	$ 185.00	$ 155.83	+ $ 29.17
2. Local travel	380.00	565.56	- 185.56
3. Printing	20.00	12.68	+ 7.32
4. Transcription machine	200.00	169.32	+ 30.68
5. Computer costs	200.00	.00	+ 200.00
6. Dissemination	400.00	237.06	+ 162.94
(Total direct costs:	1385.00	1140.45	+ 244.55
7. Indirect costs	419.00	367.22	+ 51.78
Totals:	$1804.00	$1507.67	+ $296.33

Comments

1. Supplies--As indicated in the original budget, supplies included cassette tapes and batteries for recording interviews during the study. Actual cost came close to the projection.

2. Local travel--This item involved mileage reimbursement for observations and interviews during the study. This ran somewhat higher than the projection for three reasons. First, 25 families participated in the study rather than the anticipated 15. Second, some families lived further from the researcher than anticipated. Third, mileage reimbursement increased from 21 cents per mile to 25 cents per mile in July, 1981.

3. Printing ran somewhat less than expected because it cost an

average of four cents per copy instead of the projected five cents, and because the final summaries of results were printed and distributed to participating agencies at the researcher's own expense after the funding period.

4. Transcription machine--The researcher purchased rather than rented a transcription machine, at a somewhat reduced cost. Rental of such a machine was not available in southern California, where the researcher lived during the study period.

5. Computer costs--Due to delays encountered during the study, computer analysis was not completed during the funding period. The researcher completed necessary computer work at her own expense after the funding period.

6. Dissemination costs included meals, lodging, mileage, and conference registration fees when the researcher presented study procedures, results, and implications at the annual conference of the California State Federation--Council for Exceptional Children in San Diego, California in November, 1981. Dissemination expenses also included the cost of transparencies used during the presentation and of a paper distributed to interested participants at the presentation. Since San Diego, the conference site, was relatively close to the researcher's home, travel expenses to attend the conference were less than anticipated.

7. Indirect costs were calculated at 32.2% of the direct costs.

Total direct costs came within approximately $45.00 of the projections, not including the unused budget allocation for computer costs.

TABLE 1

Summary Information on Participants

Family number	Child's sex	Child's age in months	Parent(s) in home	Parent(s) at evaluation	Parent(s) interviewed	Evaluating agency	Evaluator(s)	Evaluation setting
1	B	12	M	M	M	G	OT	O
2	G	34	M	M	M	T	T	O
3	B	2	M,F	M	M,F	H	P,OT	P
4	G	6	M,F	M,F	M,F	G	P	P
5	G	7	M,F	M	M,F	G	OT	O
8	G	5	M,F	M,F	M,F	T	PT	O
9	G	8	M	M	M	R	S,N	H
10	B	24	M,F	M	M	P	OT	P
11	G	13	M,F	M	M	P	P	P
12	G	9	M,F	M,F	M,F	P	P,OT	P
14	G	6	M,F	M,F	M,F	H	OT	O
16	G	6	M,F	M	M,F	H	P	O
17	B	9	M,F	M	M,F	P	P	P
18	G	9	M,F	M	M,F	P	OT	P
20	B	27	M,F	M	M,F	R	S,N	H
21	B	30	M	M	M	R	S,N	O
22	B	11	M,F	M,F	M,F	P	P	P
24	B	34	M,F	M	M,F	G	OT	P

Notes:
Child's sex: B = boy, G = girl
Child's age: age at time of evaluation, in months
Parents: M = mother, F = father
Evaluating agency: G = genetics department at a hospital; T = agency providing occupational, physical, and speech therapy; H = follow-up hospital clinic for children from neonatal ICU; R = agency coordinating services and providing referrals to programs; P = early intervention program
Evaluators: OT = occupational therapist; PT = physical therapist; P = psychologist; S = social worker; N = nurse; T = multidisciplinary team of child development specialists
Evaluation setting: O = hospital clinic room or other office; P = a room set up for children to play in or attend a developmental program; H = child's home

Flow Chart of Analysis Procedures

Question	Analysis Procedure	Analysis Product	Functions of Analysis Product	Relationship to Implications
I. Identification of themes				
A. How do parents react to their child's first developmental evaluation?	A. Identification of themes in interview transcriptions	A. Categorized list of interview themes concerning issues before, during, and after evaluations; frequency of occurrence for each theme	A. Interview themes 1. describe concerns and needs common to different parents in study 2. identify aspects of evaluations that parents see as important 3. point to parents' suggestions for design of evaluations	A. Interview themes identify issues for developmental evaluators to consider 1. when forming a picture of parents before an evaluation 2. when arranging an evaluation situation to meet parents' needs
B. How do parents approach their child's first developmental evaluation?	B. Identification of themes in pre-evaluation questionnaires	B. Categorized list of pre-evaluation themes; frequency of occurrence for each theme	B. Pre-evaluation themes 1. describe parents' knowledge when approaching an evaluation 2. describe parents' expectations for evaluations	B. Pre-evaluation themes identify issues for evaluators to consider 1. when forming a picture of parents before an evaluation 2. when arranging an evaluation to meet parents' needs

TABLE 2

Question	Analysis Procedure	Analysis Product	Functions of Analysis Product	Relationship to Implications
II. Comparisons across time				
A. As a group, do parents' reactions to evaluations change over time?	A. Comparison of theme frequencies within domains (i.e., theme categories) at different times	A. For each theme category, list of themes with frequencies in pre-evaluation questionnaires, initial interviews, and follow-up interviews	A. Comparisons of theme frequencies at different times 1. show continuity of parents' concerns across time 2. point to parents' inability to independently form specific questions before an evaluation	A. Comparisons of theme frequencies at different times 1. confirm importance of interview themes as expressions of parent reactions 2. lead to implications about preparing parents for evaluations
B. As individual families, do parents' reactions to evaluations change over time?	B. Comparison of theme occurrences within families during initial and follow-up interviews	B. For each theme, list of family numbers indicating mention of theme in each interview	B. Comparison of theme occurrences within families show continuity of parents' concerns across time	B. Comparison of theme occurrences within families confirm importance of interview themes as expressions of parent reactions

TABLE 2 continued

TABLE 2 continued

Question	Analysis Procedure	Analysis Product	Functions of Analysis Product	Relationship to Implications
III. Analysis of parents' ratings of evaluation features				
A. How satisfied was this group of parents with their children's evaluations?	A. Tally of evaluation features rated "helpful" and "disturbing" on Likert-type questionnaire	A. Bar graph comparing number of "helpful" versus "disturbing" responses	A. Provides picture of parents on the whole satisfied with their children's evaluations	A. Implies that parents' suggestions for evaluations arose from 1. positive features they would want repeated 2. ideas for improvement spoken from a basically satisfied (i.e., not angry) stance
B. What features of developmental evaluations hold importance for parents?	B. Tally of evaluation features rated "neutral" on Likert-type questionnaire	B. Chart showing frequencies of "neutral" ratings for individual questionnaire items and identifying items with high frequencies	B. Frequencies of "neutral" ratings 1. show that most of the questionnaire items were important to parents 2. identify four items of relatively low importance	B. Frequencies of "neutral ratings 1. confirm importance of interview themes as expressions of parent reactions (because parents rated related questionnaire items as important) 2. suggest clarifications of four themes

TABLE 2 continued

Question	Analysis Procedure	Analysis Product	Functions of Analysis Product	Relationship to Implications
IV. Exploration for relationships between evaluation features and parent reactions				
A. What features of developmental evaluations seem to affect parent outcomes four months later?	A. Matching initial interview ratings to follow-up interview ratings for related items	A. Tables showing number of matched ratings for related interview ratings	A. Tables identify evaluation features for which ratings match parent outcome ratings	A. Items with highest numbers of matches suggest possible relationships between these evaluation features and the corresponding parent outcome. These possible relationships suggest ways to arrange evaluations to encourage these outcomes
B. What features of developmental evaluations seem to affect parent reactions?	B. Identification of themes in reasons for accurate predictions of parent responses	B. Themes underlying accurate predictions of initial and follow-up interview ratings, organized by categories from interview themes	B. These themes identify evaluation features that seem to relate to specific parent perceptions and reactions regarding developmental evaluations	B. The identified features lead to specific recommendations about ways to arrange evaluations to encourage positive parent reactions